Engaging Diverse Patients in Using an Online Patient Portal

Principal Investigator: Courtney Rees Lyles, BA PhD

Organization:

University of California, San Francisco UCSF Center for Vulnerable Populations UCSF Division of General Internal Medicine at Zuckerberg San Francisco General (ZSFG) Hospital and Trauma Center

Project/Grant Period: 08/01/2015 – 07/31/2019 (with 12-month NCE)

Federal Project Officer: Tamara Willis

Acknowledgement of Agency Support: AHRQ

Grant Award Number: 5R00HS022408-04

Structured Abstract

Purpose: To determine barriers and facilitators to portal use among diabetes patients in a safety net setting, and develop and pilot test online training to engage such patients in portal use.

Scope: Lower-income patients such as those on Medicaid are very interested in portals. However, public healthcare organizations are behind in this process. The federal Meaningful Use incentives were the first opportunity for public hospitals like the San Francisco Health Network (SFHN) to purchase fully operational EHR systems for the ambulatory care setting.

Methods: We established two advisory groups, which met several times over the project period to inform and guide our patient-centered curriculum development process. We employed qualitative methods such as in-depth interviews (with patients, caregivers, and providers) and observational think-aloud interviews for detailed usability testing. Finally, we ran a pilot randomized trial to assess whether training could improve portal use in our healthcare setting.

Results: Our team developed a portal training curriculum, co-designed by patients. After creating the portal training curriculum, we recruited patients from two primary care clinics in SFHN to participate in the pilot RCT. 60% were non-white, 51% had limited health literacy, and 76% used the Internet daily. At 3-6 months after the training, 21% logged in to the portal and 20% initiated the portal sign-up process in their clinic.

Key Words: electronic health record, personal health record, patient portal, safety net setting, underserved populations, randomized trial

Purpose (Objectives of Study)

Aim 1: Design an Online Training Program to Educate Diverse Patients about Using a Patient Portal Relying on user-centered design methodologies, we will develop a patient-focused, interactive portal training to: 1) address barriers to portal use (e.g., concerns about security of information online), 2) walk patients through portal registration and use (e.g., creating a secure password, navigating the portal features), and 3) educate patients about using a portal website to improve the self-management of their chronic condition (e.g., reviewing lab results prior to upcoming visits, emailing about specific healthcare concerns). This process will rely on and incorporate patient feedback in all stages.

Aim 2: Randomized Pilot Trial of Online Training Implementation

We will enroll patients with chronic illness and randomly assign participants to receive the training in one of two ways: 1) self-directed by completing the online modules on their own, and 2) with one-on-one support to complete the training. Both of these groups will be compared to one another and to a non-randomized usual care group.

Scope

Background

Driven by over \$30 billion in federal incentives through the Meaningful Use program, healthcare systems rapidly adopted health information technology (HIT) systems such as patient portals that are tied to electronic health records (EHRs). These systems provide patient access to laboratory test results and medical histories, online appointment and refill functions, and secure e-mail messaging with providers. Regardless of implementation phase, all systems are looking to understand and encourage patient engagement with portals. However, there are marked racial/ethnic differences in the use of online portals – even after accounting for their access to and use of the Internet. Understanding and addressing the differences in portal use will be important for ensuring increased HIT reach, safety, quality, and efficiency for all patients.

Context

Patient access to online patient portals has the potential to improve efficiency of care and enable patients to better manage their health. This is a particularly important strategy in chronic illness management. In addition,

patients express high levels of interest in accessing healthcare information electronically, including those not traditionally targeted by HIT dissemination efforts, such as low-income patients.

Setting

The San Francisco Health Network provides primary care to over 63,000 patients/year as the city's only public healthcare delivery system, which included the Zuckerberg San Francisco General Hospital (ZSFG). The majority of patients are non-White and on Medicaid/uninsured. Launched in January 2015, the online patient portal within SFHN (called MYSFHEALTH) allows patients to access their visit summaries, lab results, and health education materials online.

Participants

Aim 1: Usability Interviews

From February to July 2015, we recruited 23 chronic disease patients and 2 caregivers with varied experience using the computer and Internet to manage their health. Participants were recruited from: (1) the Richard H. Fine People's Clinic (RFPC), a primary care clinic serving more than 6,500 patients; and (2) nurse-led diabetes support and education group sessions to which RFPC patients were referred. We recruited patients through an electronic query of patients with upcoming clinic or diabetes group appointments. Participants were eligible for the study if they were (1) English-speaking, (2) did not have a diagnosis of cognitive impairment, (3) diagnosed with ≥1 chronic diseases or the caregiver of a patient with ≥1 chronic disease, and (4) had not signed up for, seen, or used the newly launched patient portal. We defined a caregiver as someone playing a role in the management of a patient's health other than the patient or the medical provider. We limited participants to English speakers since the portal under study is only available in English. We focused on patients with chronic disease because portal use can support ongoing self-management.

Aim 2: Randomized Trial

Through an electronic query of the electronic health record (EHR), we generated a list of patients who had clinic visits prior to the study (April-July 2016) meeting the following criteria: (1) English-speaking (as the portal was only available in English in our setting), (2) age 18 or older, and (3) diagnosed with a chronic condition (as previous studies have shown that portal use is highest among those managing a chronic illness). Providers reviewed the lists and excluded individuals with cognitive or visual impairment, severe mental health conditions, or other barriers to enrollment. Through phone screening, we further excluded individuals without email addresses (as this was necessary for portal registration) and those who already self-reported using MYSFHEALTH.

The trial is registered at clinicaltrials.gov as NCT03354000.

Methods

Aim 1: Design of Portal Training

We completed and analyzed 25 thinkaloud interviews with patients. Specifically, we videotaped participants directly interacting with the portal and documented barriers (both technical and content-related) to using the site.

After completing this study, we then created extensive training content for the online tutorial about accessing the MySFHealth portal website. In partnership with the ZSFG library, we convened two advisory groups: 1) a patient advisory group made up of patients and caregivers from our healthcare system, and 2) a project advisory group made up of clinicians, health informatics leadership, literacy researchers, librarians, and community-based organizations working on increasing digital literacy skills among vulnerable patient populations in the San Francisco Bay Area. These groups met 2 times each and have helped to ensure that our work is relevant and accessible for the target audience.

Caregiver pilot analysis

Upon completion of the qualitative work and usability interviews, we recognized the gap in knowledge of caregivers' experiences with patient portals. As they are a difficult to reach population, we therefore interviewed an additional 16 providers about their experiences with caregivers in using online patient portals. We conducted 40-60 minute semi-structured interviews with providers from three large California safety-net health systems. The interviews focused on providers' experiences with caregivers and how the portal could be leveraged as a

tool to support caregivers in their responsibilities. Analysis and publication of this work is underway and forthcoming.

Aim 2: Randomized Trial

We recruited participants from 2 primary care clinics, one based on the campus of ZSFG and one community-based clinic within SFHN (using the exclusion criteria outlined above).

We randomized patients during an in-person session to receive: a) an in-person tutorial with a trained research assistant versus b) a link to access the online tutorial on their own. During this in-person enrollment session, all participants received an informational pamphlet that was disseminated within the general clinic population outlining key features of the patient portal, and were guided through the steps of signing up for a LearnerWeb account to access the training materials. For participants randomized to the in-person training arm, a trained research assistant prompted participants to log into the learning platform and guided them in accessing the training materials. The staff member provided further explanation or clarification if participants had questions about the training material. Participants in the take-home arm were given a paper handout with a link to the training materials and an outline of the steps for accessing the training curriculum. The research assistants delivering the intervention were blinded to the randomization allocation until after the consent process was complete.

Portal Sign-up and Use

Portal outcomes were assessed via EHR chart review as 1) initiating sign-up for portal access (yes/no), and 2) logging into the portal after the sign-up process was complete (yes/no and total number of log-ins). Our primary outcome was the binary assessment of portal log-on in the follow-up period of 3-6 months post-training (mean 112 days, range 82-192 days), with an estimated sample size of 100 to detect a 25% difference in portal use (10% vs. 35%) with 80% power. Because portal enrollment is tied to an in-person sign-up process, we examined portal use data after the participant's next visit whenever possible.

Clinic Comparison Group

To obtain comparison outcomes in a third usual care cohort, we performed an additional, non-randomized EHR data pull of *all* patients who had visited the 2 primary care clinics during the recruitment time period and followed them through the same follow-up period. We used the same portal use outcome ascertainment in this group.

Survey Measures

We also collected patient survey measures at baseline (in-person) and follow-up (via phone). Demographics included age, gender, race/ethnicity, highest education completed, health literacy, English proficiency, and current Internet use.

To assess portal interest/attitudes and skills, we also asked a series of self-reported items at both baseline and follow up. Interest and attitude items included 1) usefulness of Internet for making health decisions (5-point Likert from not at all to very useful), 2) importance of getting medical information electronically (3-point Likert from not at all to very important), 3) confidence in safeguards for online medical records (3-point Likert from not at all to very confident), 4) interest in using the MYSFHEALTH portal website to see their medical record (5-point Likert from no interest to high interest), and 5) interest in using specific potential portal features (4-point Likerts from not at all to very interested). Next, we assessed their self-reported skills by asking about: 1) self-rated skills to use a website to manage healthcare (5-point Likert strongly disagree to strongly agree), 2) confidence in logging into MYSFHEALTH without help (scored 1 to 10), 3) confidence in using MYSFHEALTH to improve their health (scored 1 to 10), and 4) self-reported eHealth literacy.

The follow-up surveys also included an open-ended question about the reason(s) for portal non-use among those without any log-ins documented in the EHR.

Limitations

It is important to note that a large proportion of patients in our Network were not eligible for this study, given the high number of non-English speakers and lower rates of email use in our healthcare setting. The lack of portal accessibility in multiple languages, as well as the need for a higher level of existing digital literacy skills to sign up, represent substantial barriers to use among diverse populations.

Results

Aim 1: Portal Training

Informed by documented usability barriers outlined above, we published a paper outlining the key ingredients of usability relevant for our patient population¹⁹. Most importantly, we found significant barriers by the self-reported health literacy of participants¹⁸.

	Variable	Adequate Health Literacy	Limited Health Literacy	Very Limited Health Literacy
	Tasks Completed Without Assistance (mean)	4.2	1.27	0.25
Portal	Basic Computer Barrier, n (%)	1 (10)	11 (73)	4 (100)
Navigation	Routine Computer Barrier, n (%)	9 (90)	14 (93)	3 (75)
	Reading/Writing Barrier, n (%)	3 (30)	5 (33)	2 (50)
	Medical Content Barrier, n (%)	1 (10)	4 (26)	0 (0)
	Difficulty Finding Treatment Plan, n (%)	0 (0)	5 (41)	2 (50)
Health Interpretation	Difficulty Interpreting Lab Results, n (%)	1 (10)	6 (40)	3 (75)
	Seeking Explanation From Provider, n (%)	9 (90)	14 (93)	4 (100)

Our final portal training curriculum was completed following this research. The curriculum contains simple instructions and 9 how-to videos for accessing MYSFHEALTH (getting started, signing up, signing in, creating a username, creating a password, accessing the homepage, accessing a visit summary, reviewing lab results, using the online health library – all videos available upon request). In addition, we have also created a patient video documenting a personal story about how someone might use the portal website to manage their healthcare, as well as a provider video outlining the importance of a portal website in improving care. Participants can watch all videos sequentially, or skip to relevant topics as preferred. Our iterations simplified the content to better match the digital and health literacy levels of the population. In particular, these videos used audio (with captions) for explaining the portal functionality as well as screenshots of how to access each feature. Several of the videos and content are publicly available on the SFHN website at https://www.sfhealthnetwork.org/mysfhealth-faq-and-videos/.

Aim 2: Randomized Trial

We recruited 93 patients for the randomized trial testing this curriculum. Participants were randomized into one of two arms, the first of which received in-person tutorial with a trained research assistant, and the second of which received a link to watch the videos without a trainer present. Then, 3-6 months post-training, we measured portal enrollment and logins from the electronic health record, along with patient reports of their ability and skills in using the website.

The full results of this research will be published in forthcoming manuscript(s). Overall, among the 93 participants, 60% were non-white, 51% had limited health literacy, and 76% used the Internet daily. At 3-6 months after the training, 18 participants (21%) logged in to the portal and 17 (20%) initiated the portal sign-up process in their clinic. These proportions of sign-up and login did not differ by the in-person vs. take-home training assignment. However, the rates of portal use were substantially higher than the average portal use in

the clinics during the same timeframe, with about 9% of primary care patients in these clinics logging on overall. We also saw significant pre-post improvement in participants' ratings of a) self-rated skills to access the portal and b) ratings of digital health skills. This suggests that the training can increase portal engagement compared to usual care, but was not sufficient in getting a majority of underserved patients to use the website.

List of Publications and Products (Bibliography of Published Works and Electronic Resources from Study)

Electronic Resources

As stated above, some of the final training videos created for this project have been posted on the SF Health Network website at: https://www.sfhealthnetwork.org/mysfhealth-faq-and-videos/ However, since the patient portal user interface was updated recently, the how-to videos were taken down to be updated at a future date.

Publications

We have published papers about the portal training curriculum during the grant period, as well as several additional papers applying similar usability methods or expanding understanding of portal use in safety net settings that was directly informed by the training received during my R00 award period.

- 1. Aguilera A, **Lyles CR**. The Case for Jointly Targeting Diabetes and Depression Among Vulnerable Patients Using Digital Technology. JMIR diabetes. 2017;2(1):e1.PMC6238894.
- 2. Chan B, **Lyles C**, Kaplan C, Lam R, Karliner L. A Comparison of Electronic Patient-Portal Use Among Patients with Resident and Attending Primary Care Providers. Journal of general internal medicine. 2018;33(12):2085-2091.PMC6258601.
- 3. Fontil V, McDermott K, Tieu L, et al. Adaptation and Feasibility Study of a Digital Health Program to Prevent Diabetes among Low-Income Patients: Results from a Partnership between a Digital Health Company and an Academic Research Team. Journal of diabetes research. 2016;2016:8472391. PMC5102733.
- 4. Ippolito MM, **Lyles CR**, Prendergast K, et al. Food insecurity and diabetes self-management among food pantry clients. Public health nutrition. 2017;20(1):183-9
- 5. Karter AJ, Parker MM, Solomon MD, et al. Effect of Out-of-Pocket Cost on Medication Initiation, Adherence, and Persistence among Patients with Type 2 Diabetes: The Diabetes Study of Northern California (DISTANCE), Health services research, 2018;53(2):1227-47, PMC5867086.
- 6. Khoong EC, Cherian R, Matta GY, **Lyles CR**, Schillinger D, Ratanawongsa N. Perspectives of English, Chinese, and Spanish-Speaking Safety-Net Patients on Clinician Computer Use: Qualitative Analysis. Journal of medical Internet research. 2019;21(5):e13131.PMC6549473.
- 7. **Lyles CR**, Allen JY, Poole D, et al. "I Want to Keep the Personal Relationship With My Doctor": Understanding Barriers to Portal Use among African Americans and Latinos. Journal of medical Internet research. 2016;18(10):e263. PMC5067358.
- 8. **Lyles CR**, Altschuler A, Chawla N, et al. User-Centered Design of a Tablet Waiting Room Tool for Complex Patients to Prioritize Discussion Topics for Primary Care Visits. JMIR mHealth and uHealth. 2016;4(3):e108. PMC5040865.
- 9. **Lyles CR**, Fruchterman J, Youdelman M, et al. Legal, Practical, and Ethical Considerations for Making Online Patient Portals Accessible for All. American journal of public health. 2017;107(10):1608-11. PMC5607665.
- 10. **Lyles CR**, Godbehere A, Le G, et al. Applying Sparse Machine Learning Methods to Twitter: Analysis of the 2012 Change in Pap Smear Guidelines. A Sequential Mixed-Methods Study. JMIR public health and surveillance. 2016;2(1):e21. PMC4920957.
- 11. **Lyles CR**, Gupta R, Tieu L, Fernandez A. After-visit summaries in primary care: mixed methods results from a literature review and stakeholder interviews. Family practice. 2019;36(2):206-213.
- Lyles CR, Lunn MR, Obedin-Maliver J, et al. The new era of precision population health: insights for the All of Us Research Program and beyond. Journal of translational medicine. 2018;16(1):211. PMC6062956.
- 13. **Lyles C**, Schillinger D, Sarkar U. Connecting the Dots: Health Information Technology Expansion and Health Disparities. PLoS medicine. 2015;12(7):e1001852. PMC4501812.

- Lyles CR, Tieu L, Sarkar U, et al. A Randomized Trial to Train Vulnerable Primary Care Patients to Use a Patient Portal. Journal of the American Board of Family Medicine: JABFM. 2019;32(2):248-258.PMC6647853.
- 15. Matta GY, Khoong EC, **Lyles CR**, et al. Finding Meaning in Medication Reconciliation Using Electronic Health Records: Qualitative Analysis in Safety Net Primary and Specialty Care. JMIR medical informatics. 2018;6(2):e10167. PMC5962827.
- 16. Ratanawongsa N, Barton JL, **Lyles CR**, et al. Association Between Clinician Computer Use and Communication With Patients in Safety-Net Clinics. JAMA internal medicine. 2016;176(1):125-8. PMC4701618.
- 17. Sarkar U, Gourley GI, **Lyles CR**, et al. Usability of Commercially Available Mobile Applications for Diverse Patients. Journal of general internal medicine. 2016;31(12):1417-26. PMC5130945.
- 18. Tieu L, Hobbs A, Sarkar U, Nacev EC, **Lyles CR**. Adapting Patient Experience Data Collection Processes for Lower Literacy Patient Populations Using Tablets at the Point of Care. Medical care. 2019;57 Suppl 6 Suppl 2:S140-s148.PMC6527129.
- 19. Tieu L, Schillinger D, Sarkar U, et al. Online patient websites for electronic health record access among vulnerable populations: portals to nowhere? Journal of the American Medical Informatics Association: JAMIA. 2017;24(e1):e47-e54. PMC6080722.